Northern Ireland Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Organ and Tissue Donation (Deemed Consent) Bill: NHS Blood and Transplant

11 November 2021

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:
Mr Colm Gildernew (Chairperson)
Mrs Pam Cameron (Deputy Chairperson)
Ms Paula Bradshaw
Mr Alan Chambers
Mrs Deborah Erskine
Ms Órlaithí Flynn
Mr Colin McGrath
Ms Carál Ní Chuilín

Witnesses:

Mr Anthony Clarkson	NHS Blood and Transplant
Dr Dale Gardiner	NHS Blood and Transplant
Mr Phil Walton	NHS Blood and Transplant

The Chairperson (Mr Gildernew): I welcome, via StarLeaf, Mr Anthony Clarkson, director for organ and tissue donation and transplantation, NHS Blood and Transplant (NHSBT). Can you hear me OK, Anthony?

Mr Anthony Clarkson (NHS Blood and Transplant): I can hear you loud and clear. Can you hear me?

The Chairperson (Mr Gildernew): Yes, we hear you perfectly, Anthony, thank you.

We are also joined by Dr Dale Gardiner, associate medical director for deceased organ donation. Can you hear us OK, Dr Gardiner?

Dr Dale Gardiner (NHS Blood and Transplant): I can hear you fine; I hope that you can hear me as well.

The Chairperson (Mr Gildernew): Yes, we are hearing you fine, Dale, thank you.

Finally, we are joined by Mr Phil Walton, legislation lead. Can you hear us OK, Phil?

Mr Phil Walton (NHS Blood and Transplant): I can hear you very well; I hope that you can hear me.

The Chairperson (Mr Gildernew): Yes, we are hearing you fine there. I remind members to remain on mute when they are not speaking. I will ask the panel who might lead on a particular question when

we come to members' questions. If anyone wants to add supplementary information, that is fine, but I would like someone to make the principal response in the interests of time.

Who will lead off the presentation?

Mr Clarkson: It is me, Chair.

The Chairperson (Mr Gildernew): OK. You are all welcome to our meeting this morning, and we appreciate your attendance. Go ahead, Anthony, and give us your opening remarks.

Mr Clarkson: Thank you, Chair, for the opportunity to speak to you today. I am the director of organ and tissue donation and transplantation with NHS Blood and Transplant, which is the organ donation organisation for the UK. As you have heard, I am joined by Dr Dale Gardiner, who is our associate medical director for deceased donation, and Phil Walton, who leads the operational implementation of the change in legislation. Between us, we have been involved in the planning and successful delivery of deemed consent legislation in Wales, Jersey, England and now Scotland.

I will start by saying how pleased I was to see how aligned the Bill is to the Acts in Wales and England. That approach reduces complexity and risk and allows us to draw on the wealth of experience that we have gained in working with the other countries. The alignment means that our work will ensure the development of clear, practical and, above all, safe guidance for specialist nurses and clinicians to work to. It will also reduce the time and funding that is required to implement the change in legislation.

You will have heard concerns being raised about whether organ donation is no longer a choice under an opt-out system. Our experience across the other countries demonstrates that trust is not eroded, as donation remains a choice. Furthermore, families have always been and will continue to be central to organ donation conversations. Without them, we cannot determine the last-known decision of their loved one. Furthermore, without the family, it would not be possible to collate important medical history. Without that, it is unlikely that transplant surgeons would be willing to accept and transplant any donated organs.

Integrity of medical practice in end-of-life care has improved trust in organ donation systems over the last decade. Sometimes, we hear concerns that doctors will not try to save a life because they want the organs. That is not the case; those who are caring for patients are solely concerned with providing treatment to save the life of the individual. Organ donation is considered only when all options for life-saving treatment are exhausted.

I would also like to touch on another concern that we have heard being raised, which is the notion that donation, as a freely-given gift, is affected by the proposed legislation. Organ donation is and will always be a precious gift, as each person still has the ability to choose to opt in or out under an opt-out system. Families will still be asked to support their decision. Furthermore, the Order of St John organ donation award is the public recognition of the gift that is given by the donor and is awarded posthumously to the donor's family.

If the legislation is passed, we hope that it will have the desired effect and increase organ donation. After all, that is what we all want. Furthermore, transplantation is cost-effective. I mention that because there is a focus on measures to increase consent and donation rates. However, if those organs are not used, we will not get the transplants that we need. It is, therefore, important to ensure that transplant services keep pace with the anticipated increase in donors. One of the key factors for success in donation systems is new technology, which turns previously unusable organs into usable ones, so that we can fully honour the gift of donation and the decision of the donors to save lives.

Finally, I thank the Department of Health for working in collaboration with us and others, such as Kidney Care UK and local trusts, giving us the opportunity to provide advice on implementation options as the Bill is progressed. It means that we are in a strong place to implement, should the legislation be passed.

I will finish there, Chair, and we are happy to answer any questions for us now.

The Chairperson (Mr Gildernew): OK. Thank you. My first question relates to the fact that, as you mentioned, Anthony, trust has not been eroded as a result of the legislation's implementation in other places. Will you outline for us how trust in the system was maintained? What do you put it down to?

Mr Clarkson: I will pass that to my colleague, Phil, who led the implementation and did a lot of the work on it.

Mr Walton: We might make a joint answer, Chair. From a nursing perspective, it is down to transparency around the implementation — working closely with medical colleagues in how you deliver the legislation at the bedside through the conversations that you have with families — and, specifically, it is about going out to key demographic areas and giving people an overview of how the organ donation process works. There is a lack of information in the public domain about what happens when people are admitted to hospital and the process that they go through before organ donation is even considered. Specifically, it is about focusing on the fact that organ donation is completely independent of end-of-life care or even treatment. Somebody arrives in hospital with a medical emergency, and the clinicians and nurses who look after that patient have no interest in organ donation at that point; their sole concern is saving that individual's life.

The message around organ donation is sometimes conflated with what people think happens — people being picked up from the side of the road after they have been hit by a bus, and that sort of thing — which just does not happen. We therefore spend a lot of time on messaging and on making sure that our clinicians in the intensive care unit are clear about their role in the delivery of organ donation, particularly under new legislation.

That was primarily my focus. Dale may have additional comments that would be helpful.

Dr Gardiner: As intensive care doctors, like Dr Trainor from your earlier session, we have not seen the fears that there were when Wales brought in its legislation in 2015 about a lack of trust or the undermining of the gift. We have not seen that. I still have an active job in intensive care, and I represent and work with the intensive care community. Families still see organ donation as a gift. Our doctors and nurses on intensive care know that we will respect the families and care for them. Our job is to find out what is right for that person. The legislation makes it easier. We hear over and over again how the legislation helps. It is quite scary for an intensive care doctor to go to a family, give them terrible news and then talk to them about organ donation, but the legislation has made us feel confident that we have the societal backing to have those difficult conversations with families. That is helpful for us.

From a public, societal point of view, I will speak tonight at a meeting of the British Islamic Medical Association. That opportunity has come because of the legislation change. Its members want to engage, and we want to engage with them. We want to have proper dialogue between different groups. Trust has been built, and they can see that we still respect families. We can make that point very clearly. The legislation helps us in intensive care, and it is good for helping that dialogue in society to happen.

The Chairperson (Mr Gildernew): OK. Thank you. My second question is about resources. We discussed the issue with our earlier panel. From the experience that you mentioned of being some way ahead, legislatively, with the process, what advice can you give us about the level of planning that is needed for workforce and resources, particularly given the fact that we have a very stressed workforce already and given that we need not only the consent but the capacity to improve the situation? Who will take that question, please?

Mr Clarkson: Again, Phil is probably best placed to answer. I am happy to come in, Phil, if you need me.

Mr Walton: Of course. It is important to put that in the context of what the proposed legislation might do to the increase in donation rates. Over the past three or four years, the baseline consent rate in Northern Ireland has been 64% or 65%. If the legislation goes some way to support an 80% consent rate, which we consider to be world-class, we will be looking to increase donation rates by about 10 to 15 donors a year. That, of course, is spread across about 10 intensive care units in Northern Ireland. The first point to make is that, from an organ donation capacity point of view, we do not see that increase as being unmanageable. In addition to that, those patients are already on intensive care units. As I said before, patients are admitted to intensive care units for treatment and prognostication and to have their life saved. Only when life-saving measures are exhausted will organ donation be considered. We are not therefore admitting more patients on to intensive care units solely for the purpose of organ donation; they are already there. From that perspective, again, we do not see it as an unmanageable capacity issue.

Finally, as you and others have identified, the Northern Ireland organ donation services team is stretched, and some investment will be required to make sure that we can maintain a robust service, but, again, it is not unmanageable. We have been working closely with our colleagues in the Department of Health to identify what a budget might look like to support the robust running of organ donation services. Anthony, I do not know whether you have anything to add.

Mr Clarkson: I do not think so. As you said, we have been working closely with the Department of Health on that. We would not need a huge increase in the workforce, but we would need to ensure that we are available and able to respond to any increase in donation. We have provided some figures on that, and we have shared those with our sponsors, so they have that information.

On the transplant side, there is work to be done to consider transplantation too. That involves working with the commissioners and the transplant units to ensure that they are able to respond to any increase in transplant numbers as a result of a change to the legislation. Again, because the numbers are relatively small compared with those of the other countries, the impact would not, I suspect, be unmanageable.

The Chairperson (Mr Gildernew): OK. Thank you. This is the final one from me. In an earlier session, we heard that there has been some impact from Brexit. I know that there are linkages across Europe. That has particular resonance here, given that we share a small island with another jurisdiction, and there is the potential for problems to be created. To date, what has your experience been of the impact of Brexit? What work is ongoing to address that? What needs to be considered to improve the rates for all our people?

Mr Clarkson: I am happy to have a go at that. We did extensive Brexit planning, which worked well. We have seen very little impact on organ donation and transplantation as a result of Brexit. Where an organ cannot be placed in the UK, we continue to share those across Europe, including Ireland. That will continue. So far, it has been a smooth transition, I am pleased to say, for organ donation and transplantation. We hope that that will continue.

Of course, all countries in Europe are also pushing hard to increase the number of organ donors. Every country is aiming to get to self-sufficiency as much as possible. Hopefully, we will all move in tandem towards increased donation. Of course, many countries in the world are looking at how the countries of the UK progress with the change in legislation to see whether they should consider implementing that too.

The Chairperson (Mr Gildernew): OK. Thank you.

Ms Ní Chuilín: Thank you, panel. I do not know whether you listened to the previous presentations. You are all fairly in concert with one another, which is to be expected. Everybody is trying to achieve the world-class standard of 80%. The implementation of the Bill would definitely go a long way towards reaching that target.

I asked the others a question about workforce planning, which is a persistent issue for us, and I used the example of the duty on the Minister in Wales to provide specific or bespoke resources. What are your concerns? Given that we are still coming out of a pandemic, health budgets here have been increasingly challenged, despite the fact that Executive colleagues are in agreement on the need to prioritise health. What are your concerns about the workforce issues in relation to the successful implementation of the Bill?

Mr Clarkson: I am happy to have a go at that. Phil or Dale, I am happy for you to come in.

We are all acutely aware that there is huge pressure on workforces across the whole of the UK. In fact, I speak to colleagues around the world, and, post pandemic, they are having similar issues with their healthcare workforces, as there seems to be what we are calling, very subtly, the “great resignation”.

We in organ donation have been quite fortunate, particularly in Northern Ireland. We have an experienced, stable and mature specialist nursing team, of which we are very proud. That pays dividends by creating some stability, which is useful because, with the geography, we are not able to draw on the other countries in the same way. The team has to be quite robust, and that goes back to our earlier comments.

We work closely with the teams to support them, particularly because, of course, dealing with death all the time is not easy. Post pandemic, we have seen elements of burnout. Many of the team went back to support intensive care in the wider NHS at the height of the pandemic, so we worked closely with the teams to ensure that they have support.

So far, we are pleased to say that we have been able to maintain our levels of specialist nurses. That said, we recognise that there are pressures in organ retrieval and transplantation in the wider NHS. Dale will perhaps want to comment on the wider pressures in intensive care and how they might impact. Dale?

Dr Gardiner: Thank you. It has been a terrible burden that all of society witnessed and experienced. That has very much been the case for the front line of hospitals, and a lot of intensive care units around the UK are now short of nursing staff.

On organ donation and transplantation, we hope that the commitment by MLAs and the whole Northern Ireland Assembly at least to ensure that the resource is there, whether as part of legislation or through your commitment here today and elsewhere, can be achieved. We in organ donation and transplantation have been fortunate with government support over many years, and we count ourselves grateful for that compared with other areas of the NHS. With that support, we have been able to build the success story of increased donations that you heard about from Dominic Trainor. We need your support to take the next step.

Mr Clarkson: It is also worth noting — you will know it anyway — that transplantation is a cost-effective form of treatment compared with dialysis. Therefore, it frees up funds that can go back into the wider NHS in the stretched economy that we have.

Mrs Cameron: Panel, thank you for your presentation to the Committee on this really important subject.

Phil, you touched on the circumstances in which organ donation may come about. That is really important. Do you want to take the opportunity to walk us through a particular example of organ donation, the circumstances and why the subject would be raised? Obviously, there are perceptions out there that there is more availability of organs than is actually the case. As the Health Committee, we understand that those opportunities are limited and restricted. If you could walk us through a particular example, it might be useful for anybody who is listening in.

Could you also tell us what you believe the impact of the legislation, if passed, would have on those circumstances? I am thinking about the interactions with the specialist nurses, for example.

Mr Walton: Absolutely. Thank you for the question. I will use an example that has been used in some clinical engagement events that we undertook recently. The very first point is about the rarity of organ donation as an opportunity. In general in the UK, around 600,000 deaths happen every year. Less than 1% of those people die in circumstances in which they are in an intensive care unit attached to a ventilator — a life support machine, as it is more commonly called. It is so rare for organ donation to come up as an opportunity. Once you start applying medical contraindications and that sort of thing, that 1% figure diminishes further and further.

That is the context that we are talking about. If we put into that the practical example of a patient who has had an out-of-hospital emergency, been admitted to the emergency department and transferred to the intensive care unit, they will meet a doctor like Dr Dale Gardiner or Dr Trainor, who gave evidence to the Committee earlier. They will be assessed through a series of tests, which might be a CT scan, a load of blood tests or that sort of thing, to see what can be diagnosed. Those doctors will then instigate treatments that will save that individual's life. That is the sole purpose of the admission: to save their life. That period of time could be anything from 12 hours to three weeks and anything in between. At that time, the family is at the bedside and going through that as well as the individual and those who are caring for the patient.

In that process, there will come a time when organ donation is possible and the doctors understand that every treatment instigated so far has failed and there are no further options. They will therefore have to have a conversation with the family about their loved one not surviving the admission and to tell them that they will die. As I said, that could be after 12 hours or three weeks, but organ donation is considered only at the point at which a decision has been made that the patient will not survive. We in the organ donation team will get a phone call, and somebody like me or someone from the organ

donation service will arrive, have a conversation with the consultant and discuss the possibilities. We will have to have a look around for any medical contraindications or anything like that, and then we will plan to speak to the family. We need to know who the family or the people who are close to that individual are. We will discuss how to break the bad news, how we will talk about organ donation and who will lead on what section. That discussion goes into real, minute detail, just to make sure. You get one chance to carry out this type of conversation well, and the family will remember if it is awful. We plan that conversation as well as it can be planned, and then we deliver it. Someone like Dale will lead the conversation about ending life-saving treatments, and I will lead a conversation that brings in organ donation. At that point, the family will either say yes or no to donation. If it is "no", we move down the route of ending those life-supporting treatments sooner; if it is not "no", we talk about how organ donation will progress and about the opportunities that it will present to that family.

I appreciate that I have talked for a few minutes. This legislation has an impact only during the organ donation conversation. Deemed consent legislation presents itself in a way such that it has an effect only when there is no indication at all and the family has no idea of their loved one's position on organ donation — about whether there is a registration on the organ donor register (ODR) or whether they have had a conversation about it. There are vanishingly few occasions on which this will have an impact. We have, however, heard from families, particularly in Wales, that it gives them the confidence to say, "They have not objected; they wouldn't have been unwilling; they're the type of person who would've told me that they didn't want to be a donor, given all the publicity and those sorts of things". It gives them confidence that, by supporting donation, they are doing something that is in keeping with their loved one's values characteristics and wishes.
I hope that that answers your question.

Mrs Cameron: It does. Thank you very much.

Ms Bradshaw: Thank you to the panel for coming to the Committee today. I will ask a question about whether or not you feel that we should list those organs and tissues that can be transplanted and those that cannot, and whether that should be in the Bill or in secondary legislation, which can be amended. What model do you think would work best in Northern Ireland?

Mr Clarkson: I know that you have experience of dealing with this in Scotland, Dale. I do not know whether you want to share that.

Dr Gardiner: We saw the Bills in Wales, England and Scotland as they went through. Secondary legislation makes it easier. As medicine evolves, it can be quite difficult to change primary legislation, as you know better than I do. As certain organs may be easier to transplant in the future, which we do not know yet, it makes that a lot simpler, in the same way that you can also modify any restrictions that you may need. We favour and support using secondary legislation to allow that, as the other three nations have done, but we need clear guidance. It is difficult to operate without that. We definitely need something that tells us and all of society which organs are acceptable. We recommend that the legislation be initially relevant only to the typical organs that we do — hearts, lungs, livers, kidneys, pancreases, intestines, corneas and other tissues — and not to anything else that people may think of or that may be possible or more common in the future, but not yet, while we cement the legislation.

Ms Bradshaw: As a follow-on question, do any of the other nations of the UK go further in relation to donation for clinical trials? Obviously, we are the Health Committee, and we are as much about prevention and the development of new technologies and treatment and stuff as anything else. Are any other nations doing some sort of partnering legislation to look at donations for clinical trials?

Mr Clarkson: Dale, do you know the answer to that?

Dr Gardiner: The answer is this: not at the moment, but we have just embarked on a major clinical trial in donation It is called the Statins for Improving orGaN outcomE in Transplantation (SIGNET) trial, in which we hope to recruit 80% of donation after brainstem death donors over the next four years. That is possible through grants from the National Institute for Health Research (NIHR). We are waiting for Belfast to come online for that trial, hopefully within the next few weeks. Big supported research can happen with or without the legislation. However, families that generally say yes to donation also say yes to research. It is in the order of 85% to 90% of families that support donation will then support research. They often get a lot of comfort from knowing that, in some ways, donation to research may save even more lives than may be saved by the initial transplant.

Mr Clarkson: That is the important point. Families are very supportive of research. As Dale said, once they support donation for clinical use, they are then very supportive of donations for research, and we facilitate that, either by donating directly to research or possibly a research tissue bank, where tissue can be used for further research.

The Chairperson (Mr Gildernew): OK. I have one question, but I will give members a final opportunity to indicate whether they wish to ask anything. When it comes to the duty to provide resource in the Welsh legislation, has that worked in the Welsh context, and would it be useful in the legislation that we are considering?

Mr Clarkson: Phil, do you want to comment on that?

Mr Walton: Yes, absolutely. I do not see that it has been utilised as part of the Welsh legislation. From an organ donation perspective, there certainly is a duty for all intensive care units and transplant units to be better staffed, so, from that side, it may well have had an impact, but we do not get to see that. From an organ donation point of view, we have not had to pull that lever, so to speak, from the Welsh Government to increase our resources. Do I recommend it? It is, obviously, a question that we can perhaps bounce to the Department of Health, but there is a note of caution about putting financial imperatives on future Ministers of Health. Whether that is the way to go forward is a consideration for you as politicians.

The Chairperson (Mr Gildernew): OK. I thank you, gentlemen, for your presentations and for dealing with members' questions. That has been a useful addition for the Committee. I wish you all the best in the time ahead in your important field of work. We share your hope that the legislation will bring an improvement in the figures and that we can increase the provision and benefits of organ donation as a result. Thank you for that.

Mr Clarkson: Thank you.

Mr Walton: Thank you.

Dr Gardiner: Thank you for your great work.

The Chairperson (Mr Gildernew): Thank you.